



WHAT'S HAPPENING

We've been busy! Please read, or at least scroll, all the way to the end so you don't miss anything!



October 19th & 20th

**Run, walk, roll or stroll to support the
FamilieSCN2A Foundation!**

Join us (virtually) the weekend of October 19 & 20 for the 5th Annual [SCN2A Warrior Challenge!](#)

This is a virtual event where you can pick the day and design the course to fit your own challenge! Whether you're sprinting 100 meters, tackling a mile, conquering a 5K, or pushing yourself for a 10K or beyond, this is your chance to make a difference. No matter the distance or location, you can run, walk, roll in a wheelchair, or push a stroller to support a great cause. Register your TEAM today and make every step count!



Register NOW!



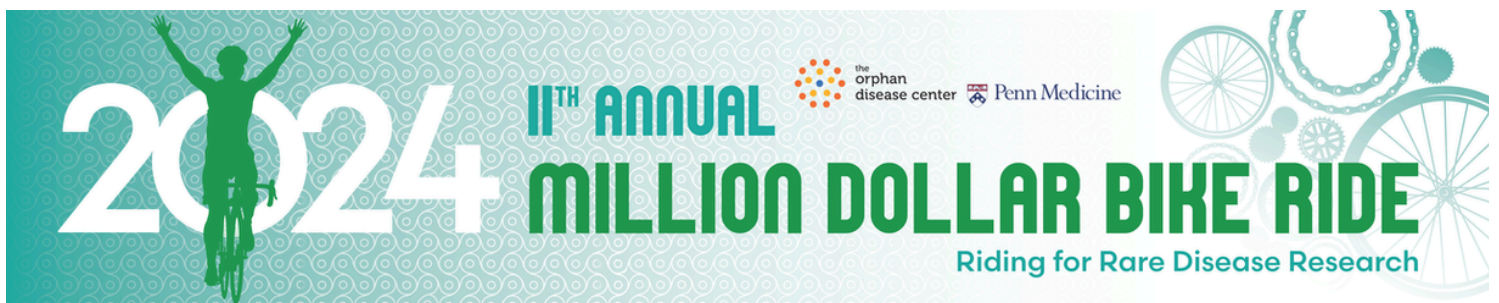
\$50K RAISED for FAMILIESCN2A in BUFFALO FUNDRAISER

We're thrilled to share that the 4th annual [Golf Fore SCN2A](#) event at Springville Country Club in Buffalo, NY was a tremendous success! Despite the rain, the Egan family, in partnership with Mobile Primary Care, hosted an amazing event that united our community in support of The FamiliesSCN2A Foundation, [#SCN2A](#) research, and awareness.

Thanks to the incredible efforts of everyone involved, we raised nearly \$50,000! We're deeply grateful to our dedicated golfers, volunteers, sponsors, and generous donors. Your unwavering commitment and enthusiasm truly made a difference!



Calling all researchers: MDBR Grant LOI Due September 20th



The MDBR Pilot Grant Program is OPEN! Thanks to our Warrior Riders Team and a match from UPenn's Orphan Disease Center, there is [a \\$62,492 grant available to study SCN2A-Related Disorders](#)!! This is a

one-year grant and it's open to the international research community. [APPLY TODAY!](#)



SCN2A IN THE NEWS

2024 Action Potential Grantees

The FamilieSCN2A Foundation has awarded its competitive Action Potential (AP) Grant to two young investigators: **Megan Abbott, MD**, a pediatric neurology specialist at the Children's Hospital of Colorado; and **Kathryn Salvati, PhD**, a postdoctoral fellow at University of California, San Francisco (UCSF).

Grantees each received \$75,000 to further their SCN2A research. The FamilieSCN2A Foundation is confident that these grants will act as a catalyst towards the vision of a world with effective treatments and cures for all SCN2A-related disorders.

[LEARN MORE](#) about Dr. Abbott (below left) Dr. Salvati (below right), their projects, and the AP Grant.





Attention all Federal Employees and Retirees!

We are thrilled to share that we are taking part in the [Combined Federal Campaign](#) starting this year! Federal employees and retirees, keep an eye out for us in the CFC charity list. Our CFC donor designation code is **85766**. Your support will make a meaningful difference in our community. Your donations, regardless of size, send a powerful message of hope to our brave families! Pledging has already commenced! [LEARN MORE](#)



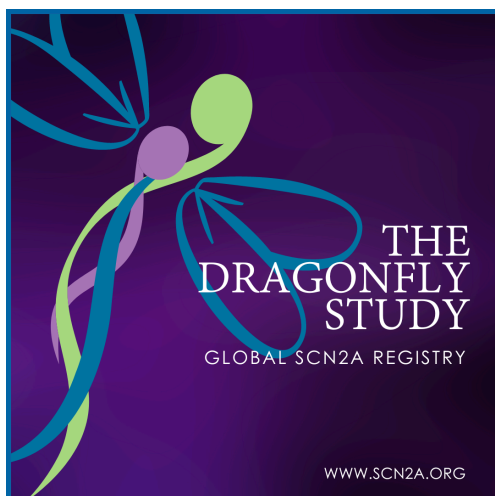
SCN2A-Focused Care at UTHealth Houston

The new Multidisciplinary Center — the first of its kind in the world — is led by faculty members with McGovern Medical School at UTHealth Houston. Providers treat both children and adults with SCN2A-related disorders, offering genetic counseling; specialized care for epilepsy, autism, and movement disorders; and access to other subspecialties. For an appointment, [complete the form here.](#)

Stay Tuned for an additional MDC location to be announced in January 2025!



GET INVOLVED



Soar with SCN2A & Join the Registry Where Dragonflies Inspire HOPE!

Welcome to The DRAGONFLY Study, a registry dedicated to individuals and families impacted by SCN2A-related disorders, serving as a central hub for sharing patient experiences and contributing vital information to drive research forward.

Join us in building a stronger, more informed community and making a lasting impact on the understanding and treatment of SCN2A-related disorders. [LEARN MORE & REGISTRATION](#)



Photo submissions for our 2025 Calendar is fast approaching!

Ready to give your Warrior a fresh new look in our upcoming calendar? Send in your updated photos to community.support@scn2a.org by September 30th.

Don't miss out – the new calendars will be available for purchase starting this November!



SCN2A UNRAVELED

Promising Initial Relutrigine (Prax-562) Clinical Data



By Shawn Egan, PhD, Chief Scientific Officer, FamilieSCN2A Foundation

[Praxis Precision Medicines](#) put out a [press release](#) this week announcing the early data from their Prax562 Phase 2 trial.

The initial phase 2 data for Relutrigine (Prax-562) looks promising for our community, and the update that the trial is expanding to a registrational trial (instead of starting a new study) is good news because it could mean a shorter time to potential approval. Although it's still early days with only seven SCN2A patients dosed, the initial data suggest that Relutrigine could have a material benefit for our early-seizure onset (more gain-of-function) SCN2A community. The trial showed improvements in seizures, communication, disruptive behaviors, and alertness—areas our community has highlighted as major unmet needs.

[LEARN MORE](#)

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or otherwise on the website or social media platforms does not constitute or imply the FamilieSCN2A endorsement, recommendation, or favoring by the Foundation. We encourage any interested participants to research, consult with your doctor, ask questions, and get input from multiple, unbiased resources.

<https://www.scn2a.org/research-scn2a.html>

The FamilieSCN2A Research Roundtable: A Family Perspective



"Hearing the updates from the scientists, listening to their discussions about overcoming gaps in academic research and barriers to drug development, and conversing with them about their findings fills me with relief and hope."

We recently asked Kellie Woodhouse and Jonathan DuCharme to share their experiences attending the SCN2A Research Roundtable as parents of a child with an SRD. It is crucial that the patient voice is integral to everything we do at the FamilieSCN2A Foundation. Please take a minute to [read about Adeline and the positive impact of attending a Family and Professional Conference](#).



WELCOME TO THE TEAM



Please welcome **Geoff Whitman** to the FamilieSCN2A Foundation Board of Trustees! Geoff is, first and foremost, father to sons Gryphon and Jack and husband to wife, Jemina.

Geoff is an ardent believer in the statement "where there is a will, there is a way" and that genetic diseases can become a thing of the past with advances in research, treatment and education. He finds inspiration in his family for all things but especially in his 13-year-old son Gryphon, who has a published, disease-causing mutation of the SCN2A gene. It is Geoff and Jemina's belief that by working with the FamilieSCN2A Foundation the lives of individuals like their son can be improved.

Geoff has spent his career as an executive in the wine and spirits business. He currently serves as Executive Vice President of Lloyd

Cellars and Prescription Vineyards, a Napa based fine wine producer. [Learn more about Geoff HERE!](#)



Welcome **Lindsay Krauskopf** as she joins our volunteer Community Support team!

Lindsay lives in Michigan with her husband, Dan, and their three children: Juliet, Elijah, and SCN2A Warrior, Miles. Formerly a clinical therapist (LPC), Lindsay now devotes her time to meeting the challenging needs of her children, especially Miles, who requires extensive medical and therapy support.

Lindsay is thrilled to be part of our Community Support team, aiming to help families feel supported and valued in the unique journey of navigating an SCN2A diagnosis.

[Learn more about Lindsay HERE!](#)



We are happy to have **Victoria Opthof-Cordaro** join our mighty team of volunteers in the mission to proclaim 2/24 as SCN2A Awareness Day in all 50 states!

Victoria an attorney residing in Bethlehem, PA, with husband, Nicholas, daughter, Dahlia, and SCN2A warrior LJ who was diagnosed at the age of 2. When she left her legal career to support LJ, Victoria got involved in community organizing and special needs awareness. In 2022, she helped get February 24th recognized as SCN2A Day in the Commonwealth of Pennsylvania and spent a day in the capital lobbying and meeting legislators to further SCN2A awareness. [Learn more about Victoria HERE!](#)

Feb. 24th is the official [SCN2A Awareness Day in 12 states](#) so we only have 38 to go! SCN2A Awareness Day is key to fulfilling the Foundation's mission to accelerate research, build community, and advocate to improve the lives of those affected by SCN2A-Related Disorders around the world.

To start the proclamation process in your state in time for SCN2A Awareness Day 2025, please email community.support@scn2a.org.



COMING UP



We're excited to invite all SCN2A impacted families to our upcoming Town Hall Meetings!

These virtual gatherings provide a valuable opportunity for us to come together, share experiences, and discuss important topics related to SCN2A-related disorders (SRD).

When: Monthly on the 5th and 20th

After registering, you will receive a confirmation email containing information about joining the meeting. We hope to see you there!

[Register for Town Hall Meetings](#)



Our Contact Information

{{Organization Name}}

{{Organization Address}}

{{Organization Phone}}

{{Organization Website}}

{{Unsubscribe}}



DONATE today to support our vision of a
world with effective treatments and cures for
all SCN2A-related disorders